

Preparing for the Emergency Room or Hospital

If you need to take your baby to the emergency room or to stay overnight in the hospital, don't forget to bring:

Proof of Insurance: Medicaid card, Medicare card, or private insurance card

Clinic Card: Charity, Tulane, Sickle Cell Center or other card

Sweater or blanket to keep you and your baby warm. Emergency rooms are usually cold.

Glossary

Anemia — low number of red blood cells

Red Blood Cell — carries oxygen from the lungs to the rest of the body

Fetal Hemoglobin — the main type of hemoglobin in babies. It is different than adult hemoglobin

Hereditary — passed down from parents to children

Hemoglobin — part of the red blood cell that carries oxygen

Jaundice — yellow color of the whites of the eyes or the skin due to chemicals released from red blood cells when they die

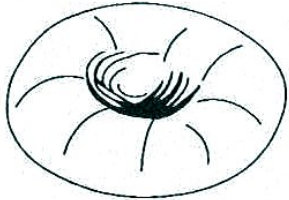
Spleen — Organ in the body that filters blood to remove old or abnormal cells and to remove bacteria

Hemoglobin SC Disease

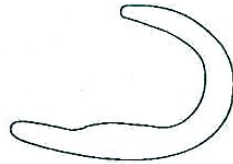


What Every Parent Should Know

Red Blood Cells bring oxygen from the air we breathe to all parts of our body. They are usually round and flexible. But in a group of disorders called sickle cell disease they can lose their shape and become stiff.



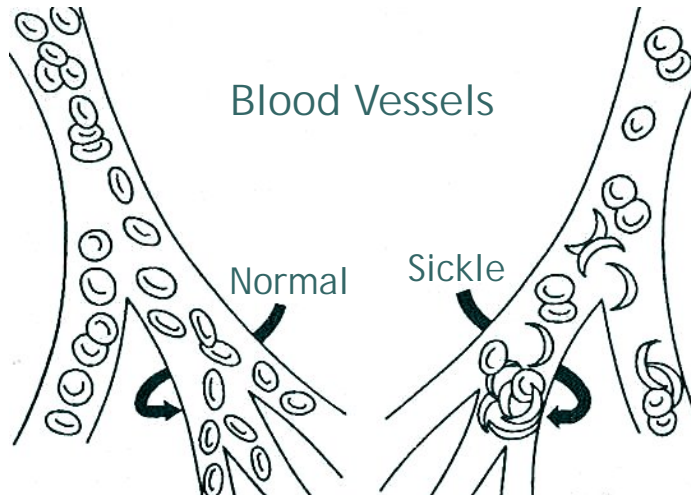
NORMAL RED BLOOD CELL



SICKLE RED BLOOD CELL

What is Hemoglobin SC Disease?

Hemoglobin SC is a form of sickle cell disease. It is an inherited disorder of hemoglobin, which is the part of the red blood cell that carries oxygen. The stiff red blood cells in hemoglobin SC disease can clog up blood vessels. They also do not live as long as regular red blood cells



Calling the Doctor

It is important to establish a relationship with your doctor and nurse so that you can get to know and trust each other. This relationship will make it easier for the doctor to take care of your baby.

When you call the doctor, he or she will need to know ...

1. Is there a fever? How high is it? You Must keep a thermometer at home and learn how to read it so you can give your doctor the exact temperature readings.



2. Did you give your baby any medicine? If yes, what kind? How much? And when was the last dose?

3. Is the baby eating and drinking? It is important for people with sickle cell disease to drink lots of fluids. Pay close attention to how much fluid the baby is drinking and let your doctor or nurse know if the baby is not drinking.

4. Is the baby vomiting?

5. Is the baby in pain? Where is the pain? Did you give the baby any pain medicine?

6. Does your baby have any of the symptoms listed before in this pamphlet?

More Warning Signs

Low energy: Your baby will have a low blood count (anemia) because sickle cells do not live as long as normal red blood cells. Usually this is nothing to worry about. The baby's body will adjust to the low blood count. But if the baby appears listless, contact your doctor right away. It could be a sign of the anemia getting worse.



Yellow eyes or Orange skin: When red blood cells die, they release chemicals into the blood. Because sickle cells die faster than normal, there are more of these chemicals around. They can cause the whites of your baby's eyes to look yellow and her skin to look orange. This is called Jaundice. Call your baby's doctor if the yellow color becomes stronger than usual.

Swollen Hands and Feet: This can be one of the first signs of hemoglobin SC disease. The baby's hands and feet feel warm and sensitive to the touch. Ask your doctor what you can do to make your baby more comfortable. This is Not an emergency.

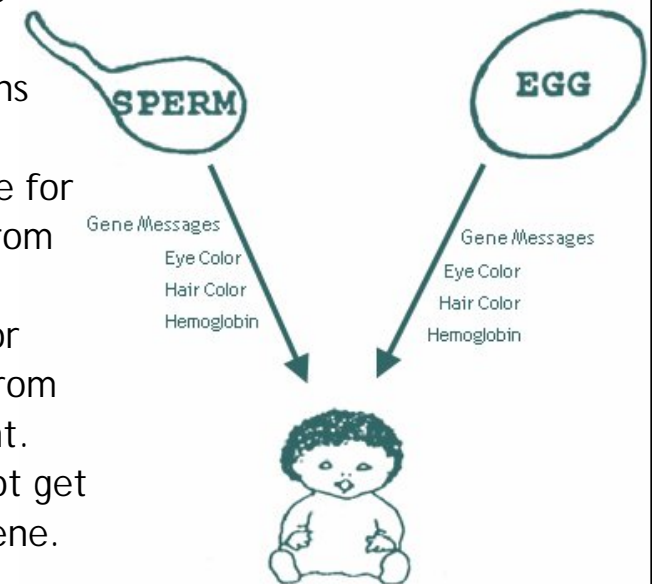
Skin Problems: Breaks in the skin can lead to serious problems in babies with hemoglobin SC disease. Sores, cuts and insect bites should be cleaned and treated with a mild antiseptic like rubbing alcohol. If the area does not heal or starts to get red or swollen, call the baby's doctor or nurse.

How did my baby get Hemoglobin SC Disease?

Hemoglobin SC disease is inherited from both parents. Just like hair color and eye color, it is passed down from the mother and father through their genes. Genes are the bits of information inside the father's sperm and the mother's egg that form a blueprint for a new life.

Genes come in pairs: for each characteristic there is one gene from the mother and one from the father. One pair of genes determines the type of hemoglobin. Most people have the normal hemoglobin call hemoglobin A. Some people get a changed hemoglobin like hemoglobin C or S.

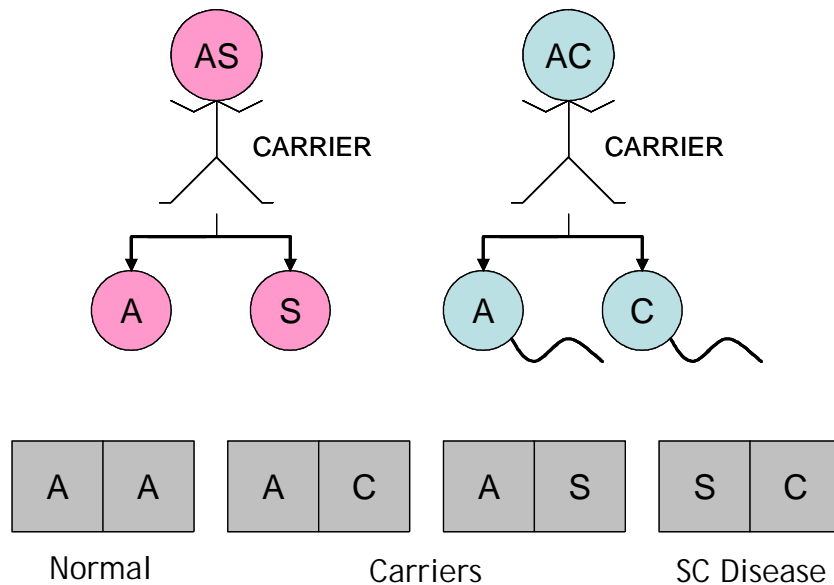
If your baby has hemoglobin SC disease, it means that he or she inherited a gene for hemoglobin S from one parent and another gene for hemoglobin C from the other parent. The baby did not get the normal A gene.



Here's How it Works ...

People who carry a gene for one changed hemoglobin do not have a disease. They are called "carriers." This means that they have one gene for normal hemoglobin A and one gene for a changed hemoglobin S or C. They have hemoglobin AS or AC.

If one parent has hemoglobin AS and the other parent has hemoglobin AC, there is a chance that the child will inherit the changed hemoglobin from each parent and end up with hemoglobin SC.



With each pregnancy there is a one-in-four chance that the child will inherit hemoglobin SC disease, a two in four chance that the child will be a carrier (AS or AC) and a one-in-four chance that the child will have a normal hemoglobin (AA).

Caring for Your Baby with Hemoglobin SC Disease

Even though your baby has a serious chronic disease, he or she will behave like other babies who do not have a medical problem. Your baby should be cared for like any other newborn baby. In general, hemoglobin SC disease is not as severe as sickle cell anemia (Hemoglobin SS disease) but many of the same problems can occur.

Here are some signs you should look out for so you can get medical care quickly when it is needed:



Fever: If your baby feels warm, take his or her temperature. If the temperature is 100 degrees, call the doctor or nurse right away. If the temperature is 101 degrees or more, take the baby to the doctor or emergency room immediately. Your baby may need to be put in the hospital and given antibiotics through a vein.

Swollen stomach, unusual sleepiness or fretfulness can be signs of Splenic Sequestration: a life-threatening problem that happens when sickled cells are trapped in the spleen. Go to the emergency room immediately. Have them call your baby's doctor. Ask your doctor or nurse to show you how to recognize this problem during a regular clinic visit.